

MINORITY ISSUES IN AIDS

Introduction

Infection with HIV constitutes a particularly severe public health problem in minority populations. AIDS affects a disproportionate number of minorities: racial and ethnic minorities represent about 22 percent of the United States population, but about 42 percent of AIDS cases. Among minorities, AIDS is more likely to affect heterosexuals as well as homosexuals. Moreover, many HIV-infected minorities are already the victims of drug dependence--and so, indirectly, are most of the minority children with AIDS. Often these HIV-infected minority populations--economically and educationally disadvantaged, alienated from society--are already underserved by the health care system.

Clearly HIV infection in minorities poses special challenges to the PHS. To meet these challenges, PHS is undertaking a number of initiatives. These include efforts to prevent the spread of HIV infection in racial and ethnic populations through culturally appropriate educational and outreach activities, to curtail HIV transmission through IV drug abuse, to ensure minorities access to clinical trials, to provide health care services to persons currently infected, and to develop a data base that will permit the PHS to target its efforts appropriately.

Background: The Minority Perspective

Of the more than 74,000 cases of AIDS reported to the CDC as of late September 1988, 26 percent (more than 19,000) have occurred in the black population and 15 percent (nearly 11,000) have occurred in the Hispanic population; the number of cases is about 1 percent in Asians/Pacific Islanders and less than 1 percent in American Indians/Alaskan Natives. It is not known precisely how many minorities are among the 1 million to 1.5 million Americans estimated to be infected with HIV, nor what the current rates of infection are.

Because most (about 80 percent) of all the AIDS cases attributed to IV drug abuse (without other risk factors) have occurred among minorities, HIV transmission among minorities is often viewed in the context of drug abuse. However, several routes of transmission are significant. IV drug abuse and homosexual/bisexual behavior each account for

roughly 40 percent of the AIDS cases among minorities. (Among blacks with AIDS, 38 percent are homosexual/bisexual men, 38 percent are IV drug abusers, and 7 percent are both; the comparable figures for Hispanics are 44 percent, 39 percent, and 7 percent, respectively.) In contrast, 78 percent of AIDS cases among whites occur in homosexual/bisexual men.

Heterosexual transmission, which accounts for only 1 percent of the AIDS cases in the white majority, is responsible for 11 percent of the cases in blacks and 3 to 4 percent in the other minority groups. Women account for 14 percent of AIDS cases among minorities, but only 4 percent among whites.

As of late September, of the more than 1,100 cases of AIDS diagnosed in children under 13 years of age, 76 percent involve minorities--53 percent are blacks, 23 percent Hispanics. Most of these children--78 percent--have contracted the disease at or near the time of birth from their HIV-infected mothers, and most--77 percent--are from families where one or both parents are IV drug abusers.

The problem of AIDS among minorities is compounded by a variety of socioeconomic factors. Minority communities often include a large proportion of people who are trying to cope with poverty, unemployment, lack of health insurance, poor health, lack of access to adequate care, and educational disadvantages. In such a setting the additional stigma of AIDS can further alienate the individual from society.

All of these factors--high incidence, diverse patterns of transmission, the problems of drug abuse, involvement of women and children, socioeconomic burdens--are critical considerations for PHS in planning effective programs directed to minority communities. This PHS effort clearly will require the development of targeted prevention and health service strategies.

Beyond these specific concerns, AIDS has brought into sharper focus longstanding inadequacies in disease prevention and health care delivery in minority communities. The PHS AIDS program may have a unique opportunity to provide a mechanism to build infrastructure and capacity to address not only HIV-related diseases, but the larger systemic public health problems related to disease prevention and health education, access to and delivery of health care, and the supply of health professionals. However, local "empowerment" is an essential element. PHS, in cooperation with State and local governments, can promote this

end by increasing the capacity of established minority community networks to take an active and responsible role.

Overarching Issues

Five overarching issues concerning minority populations were apparent in discussions at the Charlottesville meeting:

- 1) Expanding human resources;
- 2) Expanding the knowledge base;
- 3) Developing culturally sensitive communications;
- 4) Alleviating HIV-related discrimination; and,
- 5) Strengthening community networks.

Issue 1: Expanding Human Resources

The effort to control the spread of the HIV will require more public health personnel at every level of the health care system, from the laboratory to the hospital to the community. These individuals must be prepared to face the challenges presented by AIDS, and also be sensitive to the needs of minorities.

An important component of this effort will be to increase minority representation among health professionals. At present, too few minorities are trained as basic researchers, epidemiologists, biostatisticians, clinical trial and clinical laboratory personnel, outreach workers, and health care providers to combat the AIDS epidemic in minority populations. In the short term, existing personnel should be provided with additional training; in the longer term, more minorities must be recruited into the health professions. The historically black colleges and medical schools are an important source and should be utilized and strengthened to increase human resources for combatting AIDS.

Issue 2: Expanding the Knowledge Base

To develop programs leading to the prevention and control of HIV infection in minority populations, better information is needed in two major areas. Surveys and other sources of information on socioeconomic factors, health status, demographic characteristics, and behavior need to include sufficient numbers of racial and ethnic

minorities to permit valid statistical conclusions for program planning. In addition, more must be learned about the natural history, epidemiology, and clinical manifestations of HIV infection in minority populations.

Accurate national and local data are needed for each racial and ethnic group, as well as selected subgroups, to project AIDS incidence rates under varying assumptions, while information from knowledge, attitudes, and behavior surveys of minority populations as well as their care givers is needed for planning effective public health policies.

Using special sampling practices in health surveys could provide meaningful statistics on the minority population at risk. This could be accomplished by expanding the size of the racial and ethnic minority samples in current surveys, as well as by developing additional surveys directed at specific minority populations. One such example is the Hispanic Health and Nutrition Examination Survey.

Furthermore, data analyses need to be broadened to take into account the impact of social and economic factors on the health outcomes of HIV infection in minorities. It is well known that social class, independent of race or ethnicity, is a powerful influence on health and behavior problems. Moreover, minorities on average have substantially lower incomes than the general population. Datasets on racial and ethnic minorities need to include variables on income, education, and other measures of socioeconomic status that can be analyzed to better understand and hence target AIDS services to specific minority populations.

The rates of infection and the clinical manifestations of HIV disease need to be delineated for different subsets of the HIV-infected population. There is a need for clinical trials and longitudinal studies that enlist racial and ethnic minority populations and include members of every risk behavior group. Clinical trials in general should be designed to increase minority access and participation. Information also needs to be developed and analyzed on the role of genetic and environmental factors.

Ultimately, behavior, not race or ethnicity, determines risk of HIV infection. It is important that data be analyzed in a way that illuminates the relationships among behavior and race, ethnicity, socioeconomic status, and other factors. For example, economic and cultural factors appear to play a role in possible differences in needle-sharing

practices and, therefore, in differences in the HIV infection rates between white, black, and Hispanic IV drug abusers. Such specific information will make it possible to design more efficacious programs to reduce the behaviors most likely to spread HIV disease in the minority community.

Issue 3: Developing Culturally Appropriate Communications

Information, education, and outreach programs can succeed only to the extent that they communicate their message to the target populations. To be effective, community-based prevention, education and information, and other health care services need to be sensitive to the culture and appropriate to the transmission patterns prevalent in a community. Sensitivity to cultural and language differences becomes increasingly important when the subject matter is emotionally charged, even among bilingual persons who are fluent in English. Surveys as well as information on AIDS need to be targeted to different educational levels as well as cultural backgrounds, may require the use of colloquial language, or may need to be in the language of preference. A translation of material prepared for other audiences may not be as effective as material specifically designed for the minority audience. Written materials need to be supplemented by other media such as radio and television, utilizing minority-oriented stations and minority spokespersons recognized by the community.

The blood-banking community in particular needs to develop information, in culturally appropriate language, to inform potential minority blood donors of the risks, means, and consequences of HIV transmission. This will serve to protect the blood supply as well as to curtail HIV transmission.

Because racial and ethnic differences can lead incorrectly to a diagnosis of cognitive or emotional impairment, it is appropriate to establish and evaluate, in conjunction with minority members of professional societies and other minority consultants, neuropsychiatric tests that are not biased by race, ethnic, socioeconomic, or cultural factors.

Issue 4: Alleviating HIV-Related Discrimination and Stigma

Because HIV infection in minority populations combines one sensitive issue (race/ethnicity) with

another (AIDS), it can be especially stigmatizing. AIDS is also a sensitive issue because it is usually contracted through behaviors that have negative societal connotations, e.g., drug abuse, homosexual behavior, and prostitution.

Because society is strongly organized around group identifiers--race and ethnicity being among the most powerful-- and because HIV disease is proportionately greater in minority populations, there may be a tendency to stigmatize members of minority groups in general, in addition to discriminating against individuals who are infected with HIV.

Blood donor exclusion criteria, for example, must take care not to stigmatize subgroups of minorities. Exclusion criteria (such as the current exclusion of persons from areas of Africa where HIV infection is endemic) must be developed both systematically and scientifically.

In addition to being a stigma, AIDS places a huge financial burden on infected individuals and their families. This burden is especially onerous for those who are uninsured and have low incomes, persons who are overrepresented among minority populations. Minority AIDS patients may experience discrimination in getting medical care and maintaining continuity of care. Partly as a result of such discrimination, health care models that have worked in predominantly white gay communities may be inappropriate in other communities.

Issue 5: Strengthening Community Networks

Collaboration among Federal, State, and local governments and community-based organizations and institutions is essential to an effective response to the AIDS crisis. Federal efforts to stimulate effective health service delivery mechanisms need to be sensitive to the importance of the critical role played by community-based organizations, and to variations in local needs.

Greater responsibility for program design and delivery will need to be transferred to community-based organizations that effectively serve minority populations in local communities. At the same time, the active participation of credible local organizations in Federal activities may help to offset a mistrust of government information that exists in many minority communities.

More members of minorities need to participate in the design, review, and implementation of anti-HIV strategies for their local communities. Such

AIDS programs should enlist the assistance of credible and respected opinion leaders and organizations, recognizing that these leaders and organizations may differ from those that are credible to other populations.

Future Challenges

The issues raised at the Charlottesville meeting present at least three challenges to the PHS regarding minority communities. First, PHS is challenged to apply the experience and information developed in addressing AIDS to overcome other diseases in minority populations. Second, PHS is challenged to use the experience gained in addressing these overarching issues in the minority community to benefit society in general. Third, PHS is challenged to foster an ongoing partnership among cooperating PHS, State, and local government units and minority community-based organizations and institutions.

Pediatric AIDS

Background and Progress

The acquired immunodeficiency syndrome was not recognized in children until well after its initial description in adults. Initially it was difficult to distinguish AIDS from other rare congenital immunodeficiency diseases in children, but several researchers convincingly demonstrated that the human immunodeficiency virus affects the pediatric as well as the adult population. Infants and children can be infected by donor blood and blood products as well as via transmission from their infected mothers.

Of the more than 74,000 cases of AIDS reported to the CDC as of late September 1988, 1,185 were in infants and children under 13 years of age at the time of diagnosis, and 300 were adolescents 13 through 19 years of age. More than half of those in the 0 through 12 age group (672) were known to have died.

The PHS predicts an increase of almost 300 percent in pediatric AIDS, to 3,000 cases, by 1991. This estimate reflects only those children with AIDS who have been reported to CDC. It does not include other infected children who are either asymptomatic, or symptomatic at any of the earlier

stages of disease. It is likely that every child who meets the definition of AIDS, another two to ten are infected with HIV. It is estimated that, by 1991, there will be at least 10,000 to 20,000 HIV-infected children in the U.S.

Minority children, many of whom face urban poverty, poor health, lack of access to adequate health care, and educational disadvantages, comprise the majority of pediatric AIDS cases. While black children constitute 15 percent of the total U.S. child population, they represent 53 percent of all childhood AIDS cases; Hispanic children are 10 percent of the U.S. child population and represent 23 percent of all childhood AIDS cases.

Nationally, the number of infants and children with AIDS from birth through age 12 represent between 1 percent and 2 percent of all AIDS cases. In some metropolitan areas, however, the percentage of pediatric AIDS cases may be as high as 4 percent of the total AIDS cases--a variation that reflects a correlation between perinatal transmission of HIV and the number of adult drug users who are infected with HIV. Recent studies demonstrate that HIV seropositivity has reached alarming levels among childbearing women in some major cities. For example, a New York Health Department study conducted in November 1987 indicates that one out of every 61 babies born in New York City is born to a woman infected with HIV.

Evidence suggests that HIV is transmitted from infected mothers to their infants *in utero* by transplacental passage of the virus; during labor and delivery through exposure to infected maternal blood and/or vaginal secretions; and, although infrequently reported, postnatally through breast feeding. The remainder of infants and children have been infected primarily through blood transfusions or use of blood products. Most of the cases of AIDS in adolescents reported to date were the result of contaminated blood products used in the treatment of hemophilia. An increasing number of adolescents, however, are becoming infected through sexual contact or intravenous drug abuse.

Approximately 100,000 women of childbearing age in the U.S. are estimated to be infected with HIV. Many of these women are identified as infected only after their children are diagnosed as having HIV infection, including AIDS. It is not uncommon for HIV-infected women to have several pregnancies before becoming clinically ill.

Between 30 percent and 50 percent of the infants born to HIV-infected mothers are themselves infected with HIV. However, it is difficult to deter-